iConquerMS™

Building a Diverse, Engaged and Empowered Community for MS Research

Hollie Schmidt, Accelerated Cure Project
National Minority Quality Forum – April 2015
Highlights of iConquerMS™

- iConquerMS™ is a virtual national community of people with MS, linked with each other and with the research community through the iConquerMS.org portal.

- It is an initiative *by and for* people living with MS.
  - Focused on research topics of interest to people living with MS.
  - *Governed by people with MS.*

- Our national recruitment campaign launched February 2015; enrollment is underway (1500+ members); initial research studies are in the design phase.
Welcome to iConquerMS™!

Where people living with multiple sclerosis can help conquer this disease by safely and securely contributing their health information and submitting ideas for research on topics important to them.

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- It is an initiative by and for people living with MS:
  - Focused on research topics of interest to people living with MS: risk factors, treatment response, symptoms, non-drug therapies, etc.
  - Governed by people with MS.

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Who is behind iConquerMS™?

› Accelerated Cure Project, Feinstein Kean Healthcare, Arizona State University, working with people with MS developed iConquerMS™ collaboratively

› Initial funding provided by the Patient-Centered Outcomes Research Institute (PCORI, pcori.org)
   - PCORI funds patient-centered health research to assist all stakeholders in making informed health decisions

› iConquerMS™ serves nationally as the MS Patient-Powered Research Network (MS-PPRN) within PCORnet
   - 18 PPRNs and 11 Clinical Data Research Networks (CDRNs)
   - All linked through a common data model to enable efficient data exchange for collaborative outcomes research
What “Patient-Powered Research” means to us

› Making full use of the experience, opinions, and knowledge possessed by people with MS in charting a course for future research

› Recognizing that research and the breakthroughs that we all want can’t happen without the participation of people with MS – everyone is needed!

› Including people with MS in all aspects of the research process to maximize its beneficial impact on the MS community
How iConquerMS™ participants power research

› Contributing ideas and personal experiences that can be developed into research topics

› Setting the research agenda with other stakeholders

› Commenting on individual studies to improve their design and likelihood of success

› Contributing data (online queries/surveys, EHRs, apps) and biological samples for research

› Participating in results analysis and dissemination

› Encouraging others in the MS community to get involved
Diversity goals for iConquerMS™

Important for iConquerMS™ to reach and invite as many people with MS as possible

- Allows for robustness of input into the governance and activities of iConquerMS™; diversity of ideas and opinions
- Ensures that our research agenda meets everyone’s needs
- Ensures that the results of individual studies are broadly applicable to the US MS population; distributes benefits of research evenly

Diversity characteristics defined by PCORI: Race/ethnicity, socioeconomic status, health literacy, severity of disease, and age
Challenges we face in ensuring diversity

How to set goals and measure the success of our efforts?

- Our knowledge about the composition of the US population living with MS is limited – we don’t even know how many people in total have MS

- Incidence and prevalence studies provide some clues & new information
  - MS incidence studies using military/VA and Kaiser Permanente records find risk highest in African Americans, especially women; lower in Asians and Hispanics

- A national map of MS prevalence would be very valuable!
Challenges we face in ensuring diversity

With a limited budget, how do we communicate with everyone with MS and invite them to join?

- Different communication channels will be needed for reaching different groups
  - For instance, people with MS receive care at specialty MS clinics, general neurologists, community health centers
- Language barriers prevent non-English speakers from learning about and participating in iConquerMS™
- Messaging may need to be tailored to communicate benefits, address concerns for different groups
Challenges we face in ensuring diversity

How do we overcome the many factors that limit participation?

- Distrust, suspicion of clinical research
- Technological restrictions
  - Lack of Internet access
  - Greater use of smartphones vs. computers (need to be mobile-friendly)
  - Periodic service drops/data limits
- Others: Not enough time/too busy, don’t see the value of participating, MS symptoms (mood, dexterity, vision)
Actions and opportunities for iConquerMS™

- Create a diverse governing board (race/ethnicity, age, SES, disability, health literacy)
- Work with 3rd party intermediaries (e.g., NBNA, NHMA, NACHC)
- Collaborate with other MS organizations
- Collaborate with MS biotech/pharma companies
- Borrow best practices from other research initiatives with similar enrollment goals
- Develop messages that resonate with underrepresented groups; emphasize the benefits for their community and their empowered role in the process
- Use the communication tools on iConquerMS™ to start dialogues, listen and learn
Following up

› We would love to work with you!

› To explore and join iConquerMS™, visit iConquerMS.org

› To contact me:
  - Email hollie@acceleratedcure.org
  - Call 1-781-487-0099

Thank you for your attention!